

BioTrust Community Values Advisory Board Minutes
Monday, May 6, 2013
East Lansing, MI

CVAB Members Present

Voting Members

<input type="checkbox"/> Linda Burghardt	<input checked="" type="checkbox"/> Tedra Jackson	<input checked="" type="checkbox"/> Tressa Orthmeyer	<input type="checkbox"/> Rita Walters
<input checked="" type="checkbox"/> Karen Calhoun	<input type="checkbox"/> Joyce Kornbluh	<input checked="" type="checkbox"/> Vicki Rakowski	
<input checked="" type="checkbox"/> Denise Chrysler	<input checked="" type="checkbox"/> Neil MacVicar	<input checked="" type="checkbox"/> Stephen Rapundalo	
<input checked="" type="checkbox"/> Susan Dendrinis	<input type="checkbox"/> Mary Lou Mason	<input checked="" type="checkbox"/> Tina Reynolds	
<input type="checkbox"/> Rosalyn Beene Harris	<input checked="" type="checkbox"/> Ella Greene-Moton	<input type="checkbox"/> Viet Tran	

CVAB Designees

☒ John Roy Castillo

Community Attendees: E. Hill De Loney, Yvonne Lewis, Ann Mongoven, Tom Rich, Elizabeth Taylor

MDCH Staff: Janice Bach, Carrie Langbo

1. Welcome and Introductions... Tedra Jackson

- T. Jackson welcomed board members and guests. Introductions were made. New CVAB members, Karen Calhoun (Member-At-Large), Susan Dendrinis (MI Council of Maternal and Child Health) and Ella Greene-Moton (Member-At-Large). Quorum established.

2. Review of 3.4.13 Minutes

- T. Jackson entertained a motion to approve the 2/4/13 minutes. T. Reynolds moved to approve and V. Rakowski seconded. All members approved minutes.

3. MDCH Follow-up Report..Carrie Langbo

- CVAB Membership: March of Dimes cannot renew membership due to limited availability of representatives and the Asian Center which has yet to respond to renewal notice. MDCH will continue to renew or re-establish representation from the Asian community. The Michigan Public Health Association- Student Section has been approached for 2013/14 board membership and is currently discussing this with their board of directors. Work will continue to identify an inter-denominational faith based organization and representation from a tribal group for 2015/16 term.
- Research Use of Blood Spots: Four proposals have been approved by the MDCH Institutional Review Board and BioTrust Scientific Advisory Board for use of blood spots in their research. Please refer to the Dried Blood Spot Research Report (www.michigan.gov/biotrust) for details. One additional study has received conditional approval, and six proposals are currently under review.
- Consent Update: Rates continue to remain consistent. During March 2013, 91% of consent forms were returned of which 65% were signed, 21% were marked refused, and 14% were blank.
- BioTrust General Updates: Two posters summarizing evaluation of consent process were presented at the Association of Public Health Laboratories Newborn Screening and Genetic Testing Symposium this week in Atlanta, GA. A plenary session is also being presented by M. Kleyn, NBS Epidemiologist, on the robustness of the consented samples in the BioTrust. CVAB meeting dates and location for 2014 will be established and disseminated to the board. Work continues on BioTrust website revisions. Please provide C. Langbo with any specific comments regarding revisions.
- A brief preliminary report was given on work by M. Kleyn to evaluate the BioTrust consent process led by Dr. Michelle Lewis, Johns Hopkins University, funded through a grant from the Robert Wood Johnson Foundation. A detailed written summary will be available after peer-review publication.

4. MDCH IRB Update...*Tedra Jackson*

- T. Jackson participated in one expedited review of a BioTrust proposal since our last meeting and one additional proposal will be reviewed during this month's meeting. After declining the BioTrust, parents can still be recruited for specific studies and provide permission for use of the blood spots via informed consent for that study (barring receipt of a directive to destroy the sample). Dried blood spots can also be released with parental permission to physicians for clinical testing.

5. 2013 CVAB Priorities

- Community Education and Engagement: A summary of the work during 2009- present day is on the BioTrust website. Continued CVAB priority is reaching as many people as possible regarding options for use of legacy blood spots, collected prior to implementation of the informed consent process in 2010. Action Items include:
 - i. Board members disseminating information to members, communities and at events hosted by their organizations or held in their communities.
 - 1. Add NBS/BioTrust to community organization agendas as standing item. T. Jackson will follow-up with E. Greene-Moton.
 - 2. Develop Train the Trainer webinar for community leaders & speaker packet.
 - 3. Y. Lewis has multiple community events planned for summer 2013. Space on September's agenda will be reserved for Ms. Lewis to share feedback.
 - 4. MDCH collaboration with MI genetic counselors to inform prenatal patients.
 - 5. Ms. Dendrinis will help disseminate information to MI nursing teams.
 - ii. MDCH hosting a recognition day in September for MDCH employees (and others) commemorating 50th anniversary of NBS. Want to recognize those who have contributed to Michigan's NBS program, reach out to legislators, and showcase aspects of the program.
 - iii. MDCH working with Public Information Officer on mass media opportunities including: MI Association of Public Broadcasters, Newsmaker broadcasts, CVAB members approaching individual community editorials/newsletters.

6. Public Comments

- Ms. Elizabeth Taylor highlighted the need to ensure women were well informed and educated during an optimal time (outside of delivery). The CVAB should also strive to better embrace guests, improve hospitality of the meeting environment and emphasize the importance of hearing from non-board members- need to truly involve communities in decision-making.
- Mrs. E. Hill De Loney requested better observance of time allotted for public comments. The community should be involved in planning for dissemination of any revenue generated from the Biobank. Also expressed need to continue ongoing mass communication and education.
- Dr. Mongoven expressed need for more grand public events reaching larger number of people and evaluative measures. Summarized MSU Deliberative Juror recommendations for community education and reiterated the State of the State survey will continue to pose questions about BioTrust awareness. CVAB requested data from this survey when available.